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Cancer: Our national shame

The killing cost of drug treatment

For a health-care system based on the principle of equal access, the reality is tragically different, LISA PRIEST finds

LISA PRIEST
FROM MONDAY'S GLOBE AND MAIL

Diagnosed with ovarian cancer in July of 2004, Rhonda Morey knows she will likely not live long enough to see her girls grow up. So she has made them keepsakes: hand-stitched blankets for when they turn 13 -- they are 6 and 4 now -- and embroidered handkerchiefs for their wedding days.

There is something else Ms. Morey may leave behind, something she dreads -- as much as \$4,000 of the \$10,000 she put on her credit card to pay for cancer treatment.

The 33-year-old from South Brook, Nfld., has expended as much energy whittling down her credit-card debt as she has fighting a cancer that has invaded her kidneys, lungs, bladder and stomach lining. She sells Christmas crafts in two stores in the small logging town, clips coupons and even wrote a pharmaceutical firm requesting free anti-nausea pills -- ones she had previously rationed because, at \$30 a capsule, she simply couldn't afford them. The company sent a three-month supply.

"You have so much on your plate, like, 'Am I going to live or die?' " said Ms. Morey.

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Victoria Morey, 6, hugs her mother Rhonda. The 33-year-old Newfoundland mother of two, who has Stage 4 ovarian cancer burned up \$10,000 on her credit card bill, paying not only for transportation, lodging and other ancillary expenses travelling to St. John's, where she underwent surgery and chemotherapy, but also paying out of pocket for anti-nausea and pain medication. (*Sandor Fizli/The Globe & Mail*)

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"Then it's like, 'Oh my God, my drugs, how am I going to afford these drugs? And what happens if you don't have a credit card?'"

Those are common questions, sometimes crushing ones. In a country where health care rivals hockey as a point of national pride, an estimated 3.5 million Canadians have inadequate public or private insurance protection against the risk of catastrophic drug expenses, according to Fraser Group, a market information firm that serves the employee-benefits industry. But nowhere is it worse than in Atlantic Canada, where 600,000 people -- about 24 per cent of the population -- have no coverage at all.

Cancer patients in Atlantic Canada are often victims of geography, living in provinces where the social safety net does not include significant pharmacare coverage. For many, the moment they leave the hospital, the nightmare of how to afford cancer drugs begins.

"The feedback that we get continually is that the financial impact and the financial worries that go with the cancer diagnosis can create as much worry and concern as even the cancer itself," said Peter Dawe, executive director of the Newfoundland Labrador division of the Canadian Cancer Society.

Although Canada's health-care system is based on the principle of equal access, that has never been the case when it comes to drugs. Cancer patients who require costly drugs out of hospital receive the medicare equivalent of a kiss-off.

Those without coverage often work for small employers in the farming, fishing or tourism industries that do not offer drug programs, said Ken Fraser, president of Fraser Group. They are also the self-employed, even professionals such as doctors, lawyers and accountants. As well, some people decline coverage from employers or government programs due to premiums, he said.

"If you're not in a group plan, it's difficult to find an individual policy with adequate catastrophic drug coverage," Mr. Fraser said. "As a society, we've been able to put someone on the moon faster than we have been able to come up with a catastrophic drug plan in Canada."

The call for a national pharmacare program can be traced back 42 years to a Royal Commission on Health Services report. A national pharmacare program was also recommended by the National Forum on Health in 1997 and in the Liberal Red Book that same year.

More recently, a 2002 report by Senator Michael Kirby proposed a plan to deal with catastrophic drug costs, one in which the federal government would cover 90 per cent of expenses above a \$5,000 annual limit.

In that same year, Roy Romanow, head of the Commission on the Future of Health Care in Canada, proposed the federal government reimburse 50 per cent of public drug-benefit plans above an annual personal threshold of \$1,500.

But exhaustive study of the problem has not translated into help for patients, who live with the grim reality that life with cancer can be not only excruciating but expensive.

Consider Robert Gill, 41, who was diagnosed last year with acute myeloid leukemia, a cancer of the blood and bone marrow. He was forced to take out a bank loan to pay his \$1,000-a-month drug bill to deal with the complications of a bone-marrow transplant -- drug costs that exceed his \$820 monthly disability benefits under the Canada Pension Plan.

Since Mr. Gill, who lives in Botwood, Nfld., makes more on disability than those on social assistance, he says he cannot qualify for a provincial drug card, which would cover most of his medication costs.

"How do I survive?" Mr. Gill asked. "It doesn't give you any incentive. I try hard, every day I'm fighting this, but it's hard when you can't get any help."

Amelia Loder, 69, from Grand Bank, Nfld., found that when she required drugs for her non-Hodgkins lymphoma, being a senior didn't help. While other provinces provide coverage to some if not all seniors, household income counts in Newfoundland, and her fisherman husband's pay was too high to qualify her for a drug card.

Consequently, since last year she has spent more than \$3,000 on all her drugs, including those for cancer, of which \$1,100 was offset by a town fundraiser. In the spring of 2006, she obtained a drug card that will cover many of her current and future medications.

And then there's Ms. Morey, the former short-order cook and mother of two young girls, Victoria, 6, and Robyn Ann, 4.

With no benefits through her husband's seasonal logging work, she racked up \$4,000 in drug expenses, mostly in oral anti-nausea and anti-pain medication, and \$6,000 more for travel, food and lodging when she journeyed the 500 kilometres to St. John's for several operations and other treatment. Her annual household income, for a family of four, was only about \$27,500.

"There were times when I would look at that \$30 [anti-nausea] pill and I didn't know when I was

next going to be able to afford it," said Ms. Morey, who was supposed to take three of them a day. "I thought, 'I'm going to wait until I am really sick, then take them.' "

To cut costs, some cancer patients do what Ms. Morey did: They ration their drugs and suffer pain and nausea.

Knowing death is near, others arrange to die in hospital to avoid prescription-drug costs, according to a study by Maria Mathews, associate professor of health policy and health-care delivery at Memorial University of Newfoundland.

Dr. Mathews, the principal investigator of the study, said her findings suggest the Newfoundland and Labrador government should expand the drug program to cover the cost of all approved drugs for all patients with cancer, whether or not they are in hospital.

"Our medicare system only covers the drugs given in hospital," Dr. Mathews said. "For other things, it really depends on what province you live in."

A primary goal of the National Pharmaceuticals Strategy, a federal-provincial task force formed in 2004, was to ensure Canadians have coverage for catastrophic drugs, which are medications so expensive or used in such quantities that they cause financial hardship. While many provinces have found ways to pay for those costs, Atlantic Canada has not.

"The idea is to address those 600,000 Atlantic Canadians who don't have any drug coverage," said Bob Nakagawa, assistant deputy minister of pharmaceutical services in British Columbia, who is chair of the strategy's assistant deputy minister committee.

"Those are the ones that really come to mind, who don't have access, no matter how rich or poor or old or young they are."

Sharon Sholzberg-Gray, president and chief executive officer of the Canadian Healthcare Association, a federation of provincial and territorial health care associations, said governments are not moving fast enough. Only the principles of a catastrophic drug plan have been agreed to -- not a program, she said.

"We need it now because we have people who have no access to drugs," said Ms. Sholzberg-Gray. "It doesn't make sense to give patients drugs in the hospital but not when they leave the hospital, especially since these drugs keep people out of the hospital."

For many, the system can be baffling: In Saskatchewan, a cancer patient's anti-pain and anti-nausea medication taken out of hospital is covered by that province, yet it isn't anywhere in Atlantic Canada.

Newfoundland and Labrador announced plans to expand drug coverage for an additional 100,000 residents next year, but concerns about hefty co-payments loom.

In Nova Scotia, trying to obtain drugs can be so complicated that the Queen Elizabeth II Health Sciences Centre in Halifax last year hired a medication resource specialist to help oncology patients deal with it. Social worker Mary Lou Robertson has the job of untangling the programs for patients, which can include those offered by pharmaceutical companies.

"It's a maze," said Ms. Robertson. "Access to each of these forms is different. Some look at assets, others don't." Typically, the patient Ms. Robertson is trying to help makes \$20,000 to \$25,000 annually, has drug costs of \$700 a month and earns too much to qualify for programs.

"I see spouses going without medications they need because they are trying to support the medication bills of the other spouse," Ms. Robertson said.

As for Ms. Morey, she benefited from a door-to-door campaign organized by South Brook's former town clerk, Marlene Burton, in the community of 580 people.

"I wrote a letter that said, 'This is to confirm that we are conducting a donating effort for Rhonda Morey, seeing that she is afflicted with cancer and doesn't have the resources to pay for the medication,'" Ms. Burton recalled. In the end, her neighbours raised more than \$1,000.

Other help for Ms. Morey came when she obtained a drug card through the province. Though it pays for many of her current and future prescriptions, she said it still does not cover anti-nausea drugs taken outside of hospital.

She hopes to erase the \$4,000 in credit-card debt before she passes, not that she plans on dying any time soon. She has outlived her prognosis by almost two years already.

"Those kids are my strength," Ms. Morey said. "I don't want them to think that mom never tried."

And try she has. When doctors said there was nothing more they could do this fall, she pressed for more chemotherapy to buy time. To ease the burden of her loss, she has made her girls mementoes beyond the blankets and handkerchiefs: There are family trees tracking 13 generations and a book of mom's best recipes, including chocolate chip cookies. Ms. Morey has written too many notes to count, describing her love for her daughters.

"I'm trying to make it so that when I'm gone, it's as easy as possible. My kids know that I'm sick. They know about angels and God. I've explained everything so there are no surprises."

Except, perhaps, a proud health-care system that failed to fully cover a young mother's cancer treatment.

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